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STRESS APPRAISAL, COPING RESOURCES, AND PSYCHOLOGICAL  
FUNCTIONING IN PARENTS OF INFANTS AND TODDLERS DIAGNOSED  
WITH CONGENITAL HEART DISEASE

by

MEREDITH BISHOP

Under the Direction of Lindsey Cohen, PhD

ABSTRACT

Congenital heart disease (CHD) includes a variety of disorders that are characterized by structural defects to the heart or the coronary blood vessels that occur in fetal development. CHD occurs in 8 of every 1,000 live births. CHD often requires surgical repair and increases caregiving burden for families. The purpose of this study was to better understand the relations between illness-related parenting stress, coping resources, and psychological functioning in primary caregivers of young children with CHD. 69 parents provided demographic information and completed measures of parenting stress, self-efficacy, mindfulness, social support, and adjustment. Results revealed that psychological functioning in this sample is comparable to other chronic illness populations. In regression analyses, illness-related parenting stress was positively related and mindfulness was negatively related to psychological distress.

INDEX WORDS: Congenital heart disease, Pediatric, Parent, Caregiver, Stress, Coping, Distress

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MEREDITH BISHOP

A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of

Master of Arts

in the College of Arts and Sciences

Georgia State University

2017

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2017

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FUNCTIONING IN PARENTS OF INFANTS AND TODDLERS DIAGNOSED  
WITH CONGENITAL HEART DISEASE

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## **1 INTRODUCTION**

### **1.1 Congenital Heart Disease**

Congenital heart disease (CHD) includes a variety of disorders that are characterized by structural defects to the heart or the coronary blood vessels that occur in fetal development. CHD occurs in 8 of every 1,000 live births (American Heart Association, 2013; Bernstein, 2004), and is characterized by low oxygen saturation, cardiac shunts, or obstructive cardiac lesions. Although many defects are too mild to warrant surgical intervention, about 25% of defects are considered critical and may require a series of corrective cardiovascular surgeries or transplantation (Wray, 2006).

### **1.2 Infants with CHD**

Due to technological and medical advances in the last two decades (Soulvie, Desai, White, & Sullivan, 2012), cardiac anomalies are more likely to be identified prenatally and CHD is often diagnosed prenatally, allowing for more effective prenatal and postnatal care (Brosig, Whitstone, Frommelt, Frisbee, & Leuthner, 2007). Additionally, rather than performing corrective surgeries later in childhood, neonatal reparative operations are becoming more common in CHD (Backer & Mavroudis, 2007). Prenatal diagnosis and neonatal corrective surgery have increased the likelihood of infants born with cardiac anomalies reaching adulthood (Uzark & Jones, 2003). Although one-year survival rates for infants with critical congenital heart defects have increased from 67% to 75% in the last three decades (Oster et al., 2013), cardiac conditions and surgical interventions may negatively influence the temperament and the development of an infant with CHD. For example, infants diagnosed with CHD are at increased risk for growth impairment, neurodevelopmental delays, cognitive impairments, and emotional distress and irritability (Lobo, 1992; Marino & Lipshitz, 1991).

Growth impairment is common in infants with CHD, with up to 40% being undernourished prior to cardiac surgery (Ratanachu-Ek & Pongdara, 2011). Low birth weight, inadequate nutrition related to feeding issues and increased caloric requirements, gastrointestinal abnormalities, and the presence of genetic syndromes such as trisomy 21 contribute to growth impairment in these infants (Dees, Brown, Bakeman, & Campbell, 2000). Infants with CHD have been found to be more breathless and exhibit more vomiting while feeding compared to healthy controls (Gundermuth, 1975). In addition, infants with CHD often have higher caloric intake requirements, which can be difficult to meet through oral feeding (Weintraub & Menahem, 1993). Due to difficulty achieving adequate oral nutrition, approximately half of infants with CHD require enteral feeding tubes upon hospital discharge (Morgan, Shine, & McMahon, 2013). Inadequate nutrition and impaired growth impacts immune function and limits the infant's ability to physically explore their environment during important developmental periods (Morgan et al., 1993; Wray, 2006).

Developmental delays and cognitive impairments are common in infants with CHD and are often present before and after corrective heart surgery (Limperopoulos et al., 2000). Impairments include disorganized fine and gross motor movement, speech abnormalities, attention regulation and executive functioning difficulties, and cognitive delays (Brosig et al., 2007; Majnemer et al., 2009; McCusker et al., 2010). Developmental delays have been documented in more than 50% of newborns and 38% of infants before corrective heart surgery, many of which persist after surgery (Limperopoulos et al., 2000). Research suggests infants with genetic disorders (e.g., Down Syndrome), preexisting brain abnormalities (e.g., white brain injury, stroke), and oxygen saturations below 85% are at greater risk for developmental delays (Limperopoulos et al., 2002; Miller et al., 2007).

Evidence supports that infants with CHD have an increased risk of irritability, exhibit more intense crying and emotional reactions, and are less responsive to parents' cues than healthy infants (Norwegian Institute of Public Health, 2014). Infant temperamental disturbance, the unpredictability of the disease, and the overwhelming, uncertain, and all-consuming nature of caregiving for an infant with CHD may negatively impact parents after hospital discharge (Taks & McCubbin, 2002).

### **1.3 Parenting an Infant with CHD**

Parents report elevated levels of clinically significant psychological distress shortly after their child is diagnosed with CHD (Doherty et al., 2008). Distress may be expressed through grief, sorrow, anxiety, guilt, or anger. Parents report concerns about the uncertainty of their child's prognosis, and also the impact the illness will have on their child's psychosocial functioning and quality of life, family functioning, and family financial status (Van Horn, DeMaso, Gonzolez-Heydrich, & Erickson, 2001). Although some literature has suggested that parents' initial, acute distress decreases as the life-threatening nature of their child's cardiac illness decreases (Von Horn et al., 2001), further investigation is needed to determine if psychological distress persists.

Parents of infants with CHD typically have to manage surgical procedures and complex post-operative care for their infant. Infants with CHD often require specialty care such as neurology visits and receive early intervention services within the first years of life. These services include occupational, physical, and speech and language therapies often on a weekly basis. As adequate nutrition is crucial for infants with CHD, and can be difficult to accomplish with breastfeeding alone, parents may have to provide nutritional supplementation through tube feeding. Parents may also have to manage and administer multiple medications for their infant.

Infants with CHD also require more specific and intensive immunization schedules. In addition to these medically-related issues, parents must also adjust to temperamental disturbances common of infants with CHD (Marino & Lipshitz, 2001). The ongoing burden of caregiving can be considered a potential stressor that may increase the likelihood of psychological distress in the parents (Davis, Brown, Bakeman, & Campbell, 1998; Goldberg, Morris, Simmons, Folweler, & Levinson, 1990; Pelchat, 1999; Rempel, Ravindran, Rogers, & Magill-Evans, 2012; Tak & McCubbin, 2002).

#### **1.4 Psychological Functioning in Parents of Infants and Toddlers with CHD**

In both the general and illness-specific parenting literature, substantial evidence indicates that high parenting stress and caregiving burden were associated with psychological distress in parents (Cousino & Hazen, 2012; Gelfand, Teti, & Radin, 1992; Miller, Gordon, Daniele, & Diller, 1992). Thus, given the evidence that documents elevated parenting stress in parents of children with CHD three months after diagnosis (Torowicz, Cirving, Hanlon, Sumpter, & Medott-Cooper, 2010), during the first year (Goldberg, Morris, Simmons, Fowler, & Levison, 1990), and during the first two years (Darke & Goldberg, 1994; Gardner, Freeman, Black, & Angelini, 1996; Pelchat et al., 1999), it is not surprising that a majority of studies in the literature support that parents of children with CHD experience higher frequencies of psychological distress (Wei et al., 2015).

In a recent review of psychological health in parents of children with CHD, Wei et al. reported that a majority of evidence in the last 15 years indicated elevated levels of psychological distress (Wei et al., 2015). Lawoko and Soares (2006), for example, longitudinally examined psychological functioning among parents of children with CHD and found higher rates of depression (18%), anxiety (16-18%), somatization (31-38%), and hopelessness (16%) when

compared to parents of children with other chronic illnesses or healthy children. Of note, CHD illness severity did not predict parents' psychological distress, but caregiving burden and demand, social isolation, and financial instability all significantly contributed to the variance in parents' psychosocial functioning and adjustment (Lawoko & Soares, 2006). Similarly, Doherty et al. (2008) reported clinically elevated levels of psychological distress in one-third of mothers and nearly one-fifth of fathers of infants with CHD. Similarly, they found child illness severity, surgical status, or presence of an additional developmental syndrome did not significantly predict parents' psychological functioning over time. Rather, worry and coping mechanisms predicted variance in psychological distress.

However, some inconsistencies were reported in the levels of psychological distress experienced by this population, which the review attributes to inconsistencies in the measures used. Throughout the literature, minimal consensus exists for which constructs to use as outcomes (e.g.- stress, parenting stress, illness-related parenting stress, psychosocial risk, distress, anxiety, depression), and a very wide variety of measures has been used to examine these constructs (e.g.- Parenting Stress Index, Brief Symptom Inventory, Psychosocial Assessment Tool, Spielberger State Trait Anxiety Inventory), making comparisons of studies difficult. Given the lack of a clear consensus regarding stressors, appraisal of stressors, and psychological distress, further research is needed to describe how parents subjectively appraise the stressors specifically presented by their child's illness for providers to create and implement effective interventions for parents of children with CHD (Wei et al., 2015).

## **1.5 Parenting Stress**

Although parenting can be very rewarding, parents' adjustment to parenthood can be challenging and raising an infant can be stressful. The first years of parenting are often

characterized by infant crying, feeding issues, parental sleep deprivation, and declines in relationship satisfaction (Brazelton, 1962; Doss, Rhoades, Stanley, & Markman, 2009). The way parents appraise these stressors influences the amount and intensity of the stress experienced. Parenting stress is influenced by parents' characteristics, children's characteristics, parents' perception of their children's characteristics, and environmental and situational contexts (Abidin, 1995). It is clear that the responsibilities associated with parenting a child result in a host of stressors for parents; however, stressors may be compounded when caregiving for a child with a chronic medical condition.

### **1.6 Illness-related Parenting Stress**

Parents of infants with chronic conditions are exposed to a number of stressors beyond the normal demands of parenting. Illness-related parenting stress is measured through parents' subjective appraisals of stressors and demands related to their role as a parent of an infant with a chronic condition. The child's illness and illness-related demands contribute to illness-related parenting stress. Illness-related parenting stress is often related to parents learning of their child's diagnosis, the uncertainty of their child's prognosis, the financial burden of their child's medical care, and the management of their child's demanding treatment regimen. A systematic review of parenting stress indicates that parents of children diagnosed with a chronic condition report more parenting stress than parents of healthy children and that the stress is associated with illness-related stressors (Cousino & Hazen, 2013). Clearly, parenting children with chronic medical conditions can be challenging and stressful, and the potentially excessive caregiving burden may negatively impact the entire family (Barakat, Patterson, Tarazi, & Eli, 2007; Kazak, 1989; Kazak & Barakat, 1997). Evidence suggests parents of children with CHD experience elevated parenting stress three months after diagnosis (Torowicz, Cirving, Hanlon, Sumpter, & Medott-



Cooper, 2010), during the first year (Goldberg, Morris, Simmons, Fowler, & Levison, 1990), and during the first two years (Darke & Goldberg, 1994; Gardner, Freeman, Black, & Angelini, 1996; Pelchat et al., 1999). Due to the host of complexities associated with caregiving for a child with CHD, parents' exposure to stressors is inevitable. However, understanding parents' assessment of the impact of these stressors and their available coping resources is essential in the development of effective interventions for these families.

### **1.7 Coping Resources**

Coping resources have been defined as the interpersonal, cognitive, and behavioral processes that an individual uses to manage stress. Coping resources are relatively stable characteristics within individuals and their environment that promote adaptation to stressful events (Billings & Moos, 1982). During a stressful event, coping resources reduce stress by a) altering the event or b) regulating the negative emotions associated with the event. When stressors accumulate, it may strain an individual's coping resources and has the potential to cause psychological functioning (e.g., depression, anxiety; Wills & Langner, 1980). Given that many parents adapt to the stressors and demands associated with raising an infant with CHD, data illuminating both parenting stress and successful coping might be useful in intervention development for parents struggling with raising a child with CHD.

### **1.8 Self-efficacy**

When a person appraises their own competence to influence a stressful situation, they are more likely to respond to the situation adaptively. Bandura posited that motivation, affective states, and actions are driven more by people's subjective beliefs than what is objectively the case. Self-efficacy is the belief in one's own ability to cope with specific challenges or demanding tasks. Self-efficacy is essential when an individual is faced with elevated stress and

must persevere in their efforts to overcome obstacles or adversity (Bandura, 1997). It can be acquired or modified through mastery or vicarious experience, social persuasion, or physiological or emotional reactions (Bandura, 1997).

Bandura (1997) suggested an individual's self-efficacy may influence the relation between elevated stress and long-term distress. In the general parenting literature, perceived self-efficacy has been shown to moderate the effects of parenting stress on psychological functioning (Kwok & Wong, 2000). Parents who report low perceived self-efficacy are more likely to make internal attributions for failure, tend to give up more easily, and experience symptoms of anxiety and depression. In contrast, parents who report higher estimations of their perceived self-efficacy are less likely to have self-defeating cognitions and attributions regarding failure, experience less psychological distress, and report greater well-being (Bandura, 1995; Miller et al., 1992).

Self-efficacy may be particularly important for parents of children with chronic illnesses, as they often experience numerous stressors related to their child's illness and may doubt their ability to manage the demands effectively. Parents with lower self-efficacy may be at higher risk of distress when faced with elevated stress. Self-efficacy has been examined in parents of children with chronic illnesses to measure parents' perceived competence in managing their child's illness effectively. In a study examining self-efficacy of parents of children with undergoing a cancer treatment procedure, parents' higher self-efficacy was associated with lower distress and negative affect (Sloper, 2000).

Although self-efficacy has not been examined in parents of infants with congenital heart disease, some studies examining parenting stress have described the influence perceived parental competence has on parenting stress. Pelchat et al. (1999) compared the adaptation of parents of healthy infants, infants with CHD, and Down syndrome. They found that the parents of infants

with CHD reported the least control over their parenting and the greatest doubts regarding their competency in caring for their infant with CHD. Similarly, Goldberg et al. (1990) compared parenting stress in parents of infants with cystic fibrosis, infants with CHD, and healthy infants. The highest stress was reported by parents of infants with CHD, and again this was related to parents' sense of parental competence when caring for their child with CHD.

Self-efficacy can be increased through brief educational interventions (Edraki et al., 2014), making self-efficacy an important construct to target when stress is likely to be elevated. For parents with elevated parenting stress and lower self-efficacy in their abilities to manage their infants' care, coping resources that serve to regulate negative emotions may attenuate the impact of stress on psychological distress.

## **1.9 Mindfulness**

Mindfulness has been examined as a modifiable coping resource in several populations; it has been found to protect against negative outcomes such as stress, negative affect, and anxiety in college students, adults with chronic illnesses, and caregivers of adult patients with chronic conditions (Birnie, Garland, & Carlson, 2010; Haines, 2014). Evidence suggests that mindfulness is negatively associated with psychological functioning in parents of children with chronic illnesses (Minor, Carlson, MacKenzie, Zernicke, & Jones, 2006), but no studies to date have examined mindfulness in parents of children or infants with CHD.

Although the definition of mindfulness is not consistent across the literature, Kabat-Zinn (2003) defines mindfulness as “the awareness that emerges through paying attention on purpose, in the present moment, and non-judgmentally, to the unfolding of experience moment by moment.” Bishop et al. (2004) expanded on Kabat-Zinn's definition and operationalized the

focus on attention using two distinct features: a) self-regulation of attention and b) the adoption of an orientation of openness and acceptance.

Many studies suggest mindfulness reduces stress and negative outcomes by improving affective regulation and reducing negative affect through affect labeling (Black, Sussman, Johnson, & Milam, 2012; Creswell, Way, Eisenberger & Lieberman, 2007). A study by Creswell et al. (2007) asked participants to label a face either by affect or gender, while undergoing an fMRI. Results showed that verbally labeling affective stimuli attenuated amygdala responses (generally associated with negative affective states) and activated the medial prefrontal cortex (activated during monitoring one's own emotions) (Creswell et al., 2007). These neural correlates of mindfulness during affect labeling demonstrate the important role mindfulness plays in regulating negative emotions.

Feldman, Hayes, Kumar, Greeson, and Laurenceau (2007) conceptualize mindfulness as a response tendency that tends to be stable across situations, yet is modifiable by life experience or specific mindfulness training. Mindfulness-Based Stress Reduction (MBSR) interventions have been developed to reduce stress and negative affect and increase mindfulness in both clinical and non-clinical populations. The effects of MBSR interventions on stress have been investigated with caregivers of multiple chronic illness populations. Haines et al. (2014) reported decreases in stress and state and trait anxiety in caregivers of lung transplant patients after completing a 4-week intervention using MBSR techniques. Caregiver-patient dyads that included one patient diagnosed with cancer reported increased mindfulness and decreased stress after an 8-week MBSR intervention (Birnie, Garland, & Carlson, 2010). Parents of children with chronic conditions reported 32% reductions in stress symptoms after participation in an 8-week MBSR intervention (Minor et al., 2006). Despite data indicating heightened stress in parents of children

with CHD, MBSR interventions have not yet been investigated in this population. Mindfulness may protect a caregiver from elevated stress and strengthen a parent's ability to cope with the demands and stressors associated with raising a child with CHD (Brehaut et al., 2009).

### **1.10 Social Support**

Social support has been identified as a significant predictor of psychological functioning in parents of children with CHD (Lawoko & Soares, 2006; Tak & McCubbin, 2002). Social support networks allow for individuals to encounter socially rewarding experiences and roles in the community through interactions with others. These experiences increase regular positive affect, predictability, and stability that contribute to an individual's well-being and self-worth (Cohen & Wills, 1985). Social support may help buffer an individual from stressors or may attenuate the impact of stressors on negative psychological or physical outcomes. Perceived social support is a cognitive concept related to both objective (e.g., number in social network, dollars contributed by supporting others) and subjective social support (e.g., appraisal of the circumstances, coping) (Tak & McCubbin, 2002).

Social support provides a host of benefits. It may reduce the number of objective stressful events that occur, may reduce the intensity of a stress appraisal in response to a stressor, or it may attenuate the impact of a stress appraisal on mental and physical health (Cohen & Wills, 1985). It may be perceived that people providing social support provide resources (e.g., assistance in problem-solving, financial support), whether or not that is actually the case. If he/she has support from others in managing the stressor, the stressor is likely to have a less intense impact on the individual. The presence of a strong social network may redefine the way the stressor is appraised by reducing the stressor's potential for harm or increasing an individual's confidence in their own ability to cope with the stressor. Perceived social support

may also alleviate the impact of stressors by decreasing the perceived importance of the stress; decreasing an individual's physiological reactivity to the stress; or by facilitating healthy behaviors, coping, and self-care (House, 1981).

Therefore, the construct of perceived social support may be of particular importance in individuals and groups that are at high risk of experiencing stress and potential psychological distress. Parents of children diagnosed with a chronic illness have been found to be socially isolated from sources of support (Patterson & McCubbin, 1983). Lawoko and Soares (2003) compared the social experiences of parents of children with CHD, parents of children with other diseases, and parents of healthy children. Consistent with the pediatric literature (Horton & Wallander, 2001), the study found that low social support was associated with hopelessness and psychological functioning (symptoms of depression, anxiety, or somatization) in mothers of children with CHD.

Many studies have examined the impact of perceived social support on stress and parental psychological functioning in children with chronic illnesses. The presence of strong social support networks may explain why some parents of infants with CHD are exposed to multiple stressors but do not experience psychological distress (Patterson & Garwick, 1993). As a coping resource, social support may serve as a modifiable resource that can be targeted for parents at the highest risk of psychological distress.

### **1.11 Current Study**

Raising an infant with congenital heart disease can be very stressful and demanding. Potentially excessive caregiving burden has been found to be related to psychological functioning in the parents of infants with chronic conditions. However, psychological distress has only been reported in a percentage of parents of infants with CHD and has not been

associated with infant illness severity (Doherty et al., 2008; Lawoko & Soares, 2006). In the CHD literature, there is an emphasis on early identification of parents at risk for distress to promote and deliver early intervention. Furthermore, some parents who are exposed to multiple illness-related stressors are able to adjust to the demands and burden of their child's illness. Although the literature focuses primarily on risk factors for parental psychological distress in parents of children with CHD, many parents have adapted to the caregiving required of an infant with CHD despite high stress. Results from this study may provide implications for both identifying parents at the highest risk of psychological distress and targeting and promoting coping resources that may protect parents from psychological distress.

## **1.12 Primary Aims and Hypotheses**

### ***1.12.1 Specific Aim 1***

The first aim was to describe family demographic and child disease-related characteristics for primary caregivers of young children diagnosed with congenital heart disease.

### ***1.12.2 Specific Aim 2***

Aim 2 involved the description of illness-related parenting stress, mindfulness, self-efficacy, and perceived social support in primary caregivers of young children with CHD.

### ***1.12.3 Specific Aim 3***

The third aim of the study was to examine the extent to which illness-related parenting stress and coping resources relate to psychological functioning in primary caregivers of young children with CHD. Specifically, it was hypothesized that higher parenting stress, lower self-efficacy, lower mindfulness, and lower perceived social support would each significantly predict higher psychological distress.

## 2 METHOD

### 2.1 Participants

Participants included 69 primary caregivers, ranging in age from 21 to 50 years of age ( $M = 33$  years,  $SD = 6.66$  years) presenting with their child at a pediatric outpatient cardiology appointment at Sibley Heart Center (Emory) between October 2015 and July 2016.

An a priori power analysis using the software package G\*Power 3.1.3 calculated that a sample size of at least 81 participants would provide 80% power to detect a small effect size ( $f^2 = 0.10$ ; Faul, Erdfelder, Buchner, & Lang, 2009). This computation was based on a multiple regression model using four predictor variables. The significance level was set to  $\alpha < 0.05$  and error probability  $1-\beta$  was set to 0.80. Due to the illness-specific inclusion criteria, a limited number of eligible participants presenting to the outpatient clinic, and non-completion and return of questionnaires, a sample size of 69 was obtained, yielding power ranging from 0.11 to 0.90. Thus, the current study is underpowered to detect small effect sizes.

A majority of children were accompanied by their mother ( $n = 63$ , 91.3%), and the remaining children were accompanied by their father ( $n = 6$ , 8.7%). Thirty-two (46.4%) participants identified as “Black or African American,” 27 (39.1%) identified as “White,” two (2.9%) identified as “Asian,” three (4.3%) identified as “Native American or Alaska Native,” and five (7.2%) identified as “Other.” A majority ( $n = 43$ ) of caregivers were married (62.3%), 23 (33.3%) were single, one (1.4%) was separated, one (1.4%) was divorced, one (1.4%) did not report marital status. The average years of education was 14.94 ( $SD = 2.51$ ). Fourteen (20.2%) participants reported an annual income at or below \$20,000.00, 21 (30.4%) ranged between \$20,001.00 and \$50,000.00, 11 (15.9%) ranged between \$50,000.00 and \$80,000.00, and 19 (27.5%) reported an annual income that exceeded \$80,000.00. Four (5.8%) caregivers did not



report income. Eleven (15.9%) participants reported no other adults living within the home, 42 (60.9%) reported one other adult, 11 (15.9%) reported two other adults, two (2.9%) reported three other adults, and two (2.9%) reported four or more other adults living in the home. One participant did not report whether other adults lived in the home. A majority of parents reported having other children in the home ( $n = 46$ , 67%). Twenty-three (33.3%) participants reported having no other children in the home, 22 (31.9%) reported having one other child in the home, 11 (15.9%) reported having two other children, five (7.2%) reported three other children, five (7.2%) reported four other children, and two (2.8%) reported having five or more other children living in the home. One participant did not report how many other children were living in the home. Twenty-seven (40%) participants reported having more adults in the home than children, 20 (29%) reported having equal number children and adults in the home, and 21 (31%) reported having fewer adults than children in the home. One participant did not report on the number of children or adults in the home.

Nineteen (27.5%) participants reported having a chronic medical condition, which included asthma ( $n = 4$ , 6%), diabetes ( $n = 3$ , 4%), migraine ( $n = 2$ , 3%), chronic pain ( $n = 1$ , 1%), scoliosis ( $n = 1$ , 1%), HIV ( $n = 1$ , 1%), and multiple chronic medical conditions including CHD, asthma, diabetes, chronic pain, hypertension, scoliosis, high blood pressure, and severe allergies ( $n = 6$ , 9%). Eight (12%) participants reported having a diagnosis of a psychological disorder, which included depression ( $n = 1$ , 1%), bipolar disorder ( $n = 1$ , 1%), and multiple diagnosed psychological disorders including anxiety, depression, panic disorder, obsessive-compulsive disorder, and post-traumatic stress disorder ( $n = 6$ , 9%).

Nine participants (13%) reported their spouse or partner having a diagnosis of a chronic medical condition which included asthma ( $n = 3$ , 4%), high blood pressure ( $n = 2$ , 3%),

hyperthyroidism ( $n = 1, 1\%$ ), hypertension ( $n = 1, 1\%$ ), diabetes ( $n = 1, 1\%$ ),” and HIV ( $n = 1, 1\%$ ). Three participants (4%) reported their spouse or partner having a diagnosis of a psychological disorder, one indicating “bipolar disorder,” one indicating “anxiety,” and one indicating multiple psychological disorders.

## **2.2 Child Demographic and Illness Characteristics**

Participants were primary caregivers of patients from age 15 days to 3 years old (inclusive;  $M = 18.36$  months,  $SD = 14.03$  months). Thirty-seven (53.6%) patients were male, and 32 (46.4%) were female. In terms of race, 33 (47.8%) patients were “Black or African American,” 21 (30.4%) were “White,” five (7.2%) were “Asian,” three (4.3%) were “Native American or Alaska Native,” and five (7.2%) were “Other.” Two participants (2.9%) failed to report their child’s race. The pediatric cardiologist rated nineteen (27.5%) patients’ CHD diagnosis as “simple,” 15 (21.7%) as “moderate,” and 35 (50.7%) as “complex”. Twenty-nine (42%) CHD diagnoses were made prenatally, while 40 (58%) were made after birth. Twenty-two (32.8%) patients have undergone one cardiac surgery, 15 (22.4%) have undergone two cardiac surgeries, and seven (10.4%) have undergone three cardiac surgeries. Twenty-three (34.3%) patients have not yet undergone cardiac surgery or do not require cardiac surgery.

## **2.3 Procedures**

The study coordinator initially provided relevant study information including the aims and participant eligibility criteria to the healthcare providers and clinic staff. Prior to each clinic, the study coordinator identified potential eligible participants through review of the daily clinic schedule and electronic patient medical records. The study coordinator or trained research assistants (RA) reviewed eligibility criteria with healthcare providers upon arrival to the clinic to identify parents appropriate for recruitment. Research assistants then communicated with

medical staff regarding appropriate time to recruit eligible participants. Potential participants were recruited upon entry to their outpatient clinic exam room before meeting with their child's pediatric cardiologist. Parents who were interested in participating met with a RA who explained study procedures in greater detail and obtained oral consent from families who wished to participate. Study personnel reviewed the potential benefits and risks of participating in the study and methods used to ensure participants' privacy and confidentiality would be maintained. Participants were reminded that participation was voluntary and that they could choose to discontinue at any time without penalty.

Participants completed a demographic questionnaire and a battery of questionnaires regarding their illness-related parenting stress, self-efficacy, mindfulness, social support, and psychological distress. In total, participants spent approximately 15-20 minutes completing questionnaires. The RA was seated in the adjacent room to provide the participant with privacy, but be available for questions. Participants were generally able to complete the questionnaires during the clinic appointment ( $n = 68$ ) while waiting for their child's healthcare provider. Following completion of questionnaires, participants were given a \$10 gift card to Target and thanked for their participation.

Participants who were unable to complete questionnaires during their child's appointment ( $n = 13$ ) were sent home with a stamped and addressed return envelope and instructions for completing and returning the questionnaires. Participants provided contact information for follow-up reminders and a mailing address for sending the gift card following completion and return of questionnaires. Study coordinators and research assistants followed-up with participants over the phone one week after their clinic appointment and/or followed up with them at their

child's next appointment. Gift cards were mailed to participants who completed and returned questionnaires.

## **2.4 Measures**

### **2.4.1 *Demographics***

Demographic data was collected using questionnaire to assess information about the participant (relation to patient, age, gender, race, marital status, health status, highest education completed, family income, and days missed from work) and their child (age, gender, race, health history, and health status). Participants were also asked for contact information if they were willing to participate in follow-up or future research projects.

### **2.4.2 *Medical information***

Patients' electronic medical records were accessed to obtain medical diagnosis, time since diagnosis, and number of surgical procedures. Illness severity was calculated by one pediatric cardiologist to be used for analyses in the current study. Patients' illness severity was categorized into simple, moderate, or complex congenital heart disease. The pediatric cardiologist was guided by the pediatric cardiology guidelines (Lyle, 2013), but also relied on expertise in determining the patients' illness severity based on medical and surgical factors reviewed in the patients' medical records.

### **2.4.3 *Illness-related parenting stress***

The Pediatric Inventory for Parents (PIP; Streisand, Braniecki, Tercyak, & Kazak, 2001) was used as the primary independent measure of pediatric parenting stress. The PIP is a 42-item, self-report measure that was designed to measure the frequency and intensity of parenting stress associated with raising a child with a chronic illness across four domains (Communication, Emotional Functioning, Medical Care, and Role Functioning). Parents were asked to indicate on

a 5-point Likert scale (1 = *never* to 5 = *very often*) how often an event occurred in the past 7 days (e.g., being with my child during medical procedures). Parents were then asked to report how difficult that event was on a 5-point Likert scale (1 = *not at all* to 5 = *extremely*). The items on the PIP were summed separately to yield subscale scores that reflect the frequency of stressful events (PIP-F) and the difficulty associated with these events (PIP-D). Subscale scores were then summed to form a total score, which was used for analyses in the current study. Higher scores on the PIP represent higher levels of parenting stress. The PIP has demonstrated validity and acceptable internal consistency reliability ( $\alpha = .80$  to  $.96$ ) in examining parent well-being and illness-related stress in diverse chronic illness populations (Streisand, Braniecki, Tercyak, & Kazak, 2001). Within this sample, Cronbach's alpha was  $.97$ , suggesting strong internal consistency reliability.

#### **2.4.4 Self-efficacy**

The General Self-efficacy Scale (GSE; Schwarzer & Jerusalem, 1995) was used as the primary independent measure of primary caregivers' perceived self-efficacy when dealing with the management of their child's health. This measure is typically used in predicting the ability to cope with daily hassles and adaptation after stressful life events. The GSE is a 10-item, self-report measure of perceived self-efficacy. Parents were asked to indicate the degree to which statements related to self-efficacy applied to them on a 4-point Likert scale (1 = *not at all true* to 4 = *exactly true*). Due to the context-dependent and specific nature of self-efficacy, self-efficacy measures often require revision to reflect the context (Schwarzer, 1997). As we were specifically interested in parents' self-efficacy in regards to managing their child's illness, wording was modified to include, "in regards to my child's illness" and "related to my child's illness". The original scale has demonstrated acceptable internal consistency reliability ( $\alpha = .75$  to  $.90$ ) in

previous research and convergent validity with self-esteem and optimism; it has shown discriminant validity with anxiety, depression, and physical symptoms (Schwartz & Jerusalem, 1995). Within this sample, Cronbach's alpha was 0.92, suggesting strong internal consistency reliability. The total score was used for analyses in the current study with higher scores representing greater self-efficacy.

#### **2.4.5 Mindfulness**

The Cognitive and Affective Mindfulness Scale-Revised (CAMS-R; Feldman et al., 2007), a 10-item adaptation of the Cognitive and Affective Mindfulness Scale, was used as the primary independent measure of individual differences in dispositional mindfulness in daily life. Parents were asked to indicate the degree to which statements related to mindfulness (e.g., "I can accept things I cannot change") apply to them on a 4-point Likert scale (1 = *rarely/not at all* to 4 = *almost always*). Compared to other mindfulness scales, it is well-suited for contexts involving psychological distress and requires no previous knowledge of mindfulness or meditation (Feldman et al., 2006). It has demonstrated good internal consistency ( $\alpha = .81$  to  $.85$ ) and evidence of convergent and discriminant validity with concurrent measures of mindfulness, distress, well-being, emotion-regulation, and problem-solving approaches in the general population (Baer, Smith, Hopkins, Krietemeyer, & Toney, 2006; Feldman et al., 2006). Within this sample, Cronbach's alpha was 0.90, suggesting strong internal consistency reliability. In the current study, the global score was used for analyses with higher scores representing higher levels of dispositional mindfulness.

#### **2.4.6 Social support**

The Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, Dahlem, Zimet & Farley, 1988) is a 12-item, self-report measure that assesses an individual's perceived social

support from family, friends, and significant others and was used as the primary independent measure of perceived social support. Participants were asked to indicate the degree to which items of perceived social support applied to them on a 7-point Likert scale (1 = *very strongly disagree* to 7 = *very strongly agree*). As we are also interested in parents' perceived social support from healthcare providers, we added four additional items modeled after the original items. We replaced "friend" or "family" with "one of my child's healthcare providers." In the current study, the three original subscales and one additional subscale were summed to yield a total social support score, which was used for analyses in the current study. All three original subscales have shown acceptable internal consistency reliability ( $\alpha = .87$ ,  $\alpha = .85$ ,  $\alpha = .91$ , respectively; Zimet, Powell, Farley, Werkman, & Berkoff, 1990). Within this sample, Cronbach's alpha was 0.95, suggesting strong internal consistency reliability. Higher scores represent greater perceived social support.

#### **2.4.7 Psychological functioning**

The Brief Symptom Inventory – 18 (BSI-18; Derogatis, 2000) is an 18-item adaptation of the Brief Symptom Inventory – 53 and was used as the primary dependent measure of psychological distress. Parents were asked to indicate the degree to which certain symptoms within three domains (depression, anxiety, and somatization) have caused individuals distress in the past seven days on a 5-point Likert scale (0 = *not at all* to 4 = *extremely*). The BSI-18 has demonstrated acceptable internal consistency reliability ( $\alpha = .84$ ; Eckshtain, Ellis, Kolmodin, & Naar-King, 2010) and validity (Derogatis, 1993) in previous studies. Within this sample, Cronbach's alpha was 0.90, suggesting strong internal consistency. Higher scores are indicative of greater psychopathology. In the current study, the global severity index was used in primary

analyses; higher scores represent greater psychological distress. *T*-scores were calculated for the purpose of identifying clinical caseness.

### **3 RESULTS**

#### **3.1 Preliminary and Descriptive Analyses**

Out of the 81 participants recruited and consented for the current study, data collected for 69 primary caregivers ( $N = 63$  mothers, 6 fathers) were included in data analysis. Nine survey packets were sent home with families due to non-completion; eight participants failed to return surveys. Listwise deletion was applied to the data of four participants (i.e., two due to non-completion (more than 60% incomplete); one father identified himself as a secondary caregiver; one participant was mistakenly recruited twice).

Missing data were assessed for random occurrence or patterns using the missing data analysis within SPSS v.23.0. Overall, only 3.9% of items were missing from the dataset. Rate of missing values per item ranged from 0% to 10.1%, and 42 participants had complete data. Given the small portion of data missing (e.g. less than 5% overall) and that items were missing at random, single imputation using the expectation maximization algorithm was utilized to provide unbiased parameter estimates and improve statistical power of analyses (Enders, 2001; Scheffer, 2002). Missing data from the Pediatric Inventory for Parents, the Cognitive and Affective Mindfulness Scale-Revised, General Self-efficacy Scale, the Multidimensional Scale of Perceived Social Support, and the Brief Symptom Inventory-18 were imputed using Missing Values Analysis- Expectation Maximization within SPSS v.23.0.

Descriptive statistics were generated to characterize the sample and determine frequency and range of parent demographic variables (Table 1) and child demographic variables and illness characteristics (Table 2). Means and standard deviations of study variables (i.e., parenting stress,



social support, mindfulness, self-efficacy, and psychological distress) were obtained (Table 3). A series of independent sample t-tests were conducted to compare illness-related parenting stress frequency and difficulty ratings in our sample to parents in other pediatric chronic illnesses. Pearson product-moment correlations were used to determine bivariate relations between predictor and outcome variables (Table 4).

Table 1 Participant Demographic Characteristics (N = 69)

	<i>M (SD)</i>	<i>Range</i>
<b>Age</b>	33.16 (6.66)	21-50
<b>Education</b>	14.94 (2.51)	10-21
	<i>N</i>	<i>Percentile</i>
<b>Gender</b>		
Male	6	8.7
Female	63	91.3
<b>Relation to Child</b>		
Mother	6	8.7
Father	63	91.3
<b>Race</b>		
Black/ African American	32	46.4
White/Caucasian	27	39.1
Asian	2	2.9
Native American or Alaska Native	3	4.3
Other	5	7.2
<b>Marital Status</b>		
Single	23	33.3
Married	43	62.3
Separated	1	1.4
Divorced	1	1.4
Missing	1	1.4
<b>Approximate Annual Family Income</b>		
Up to \$10,000	7	10.1
\$10,001-\$20,000	7	10.1
\$20,001-\$30,000	7	10.1
\$30,001-\$40,000	6	8.7
\$40,001-\$50,000	8	11.6
\$50,001-\$60,000	4	5.8
\$60,001-\$70,000	3	4.3
\$70,001-\$80,000	4	5.8
\$80,001-\$90,000	3	4.3
\$90,000 and above	16	23.2
Missing	4	5.8
<b>Other Adults in the Home</b>		
Yes		
One	42	60.9
Two	11	15.9
Three	2	2.9

Four or more	2	2.9
No	11	15.9
<b>Other Children in the Home</b>		
Yes		
One	22	31.9
Two	11	15.9
Three	5	7.2
Four	5	7.2
Five or more	2	2.8
No	23	33.3
<b>Child to Adult Ratio</b>		
More adults than children	27	40
Equal number adults/children	20	29
Fewer adults than children	21	31
<b>Chronic Medical Condition</b>		
Yes	19	27.5
Asthma	4	9
Diabetes	3	4
Migraine	2	3
Chronic Pain	1	1
Scoliosis	1	1
HIV	1	1
Multiple Diagnoses	6	9
No	50	72.5
<b>Psychological Disorder</b>		
Yes	8	12
Depression	1	1
Bipolar disorder	1	1
Multiple Diagnoses	6	9
No	61	88
<b>Spouse Chronic Medical Condition</b>		
Yes	9	13
Asthma	3	4
High blood pressure	2	3
Hyperthyroidism	1	1.5
Hypertension	1	1.5
Diabetes	1	1.5
HIV	1	1.5
No	60	87
<b>Spouse Psychological Disorder</b>		
Yes	3	4
Bipolar disorder	1	1
Anxiety	1	1
Multiple Diagnoses	1	1
No	66	96

Table 2 Child Demographic and Illness Characteristics (N = 69)

	<i>M (SD)</i>	<i>Range</i>
<b>Age (months)</b>	18.36 (14.03)	0-46
	<i>N</i>	<i>Percentile</i>
<b>Gender</b>		
Male	37	53.6
Female	32	46.4
<b>Race</b>		
Black/ African American	33	47.8
White/Caucasian	21	30.4
Asian	5	7.2
Native American or Alaska Native	3	4.3
Other	5	7.2
<b>CHD Illness Severity</b>		
Simple	19	27.5
Moderate	15	21.7
Complex	35	50.7
<b>Time of Diagnosis</b>		
Prenatally	29	42
After birth	40	58
<b>Number of Cardiac Surgeries</b>		
None	23	34.3
One	22	32.8
Two	15	22.4
Three	7	10.4
<b>Other chronic condition/syndrome</b>		
Yes	18	26.1
No	47	68.1

Table 3 Descriptive Data of Study Variables

Variable	<i>M (SD)</i>	<i>Range</i>
1. Pediatric Inventory for Parents (PIP)	182.9 (56.38)	86 - 329
2. Cognitive and Affective Mindfulness Scale - Revised (CAMS-R)	27.69 (6.67)	13 - 40
3. General Self-efficacy Scale - Revised	31.41 (6.65)	10 - 49
4. Multidimensional Scale for Perceived Social Support (MSPSS)	91.90 (18.34)	21 - 112
5. Brief Symptom Inventory- 18 (BSI-18)	7.59 (8.10)	0 - 34

*Note.* PIP parenting stress scores range from 0 to 420, with higher scores indicative of higher levels of parenting stress. CAMS-R mindfulness scores range from 0 to 40, with higher scores indicative of higher levels of mindfulness. GSE self-efficacy scores range from 0 to 40 with higher scores indicative of greater self-efficacy in regards to child illness management. MSPSS scores range from 0 to 112, with higher scores indicative of greater sense of perceived social support. BSI-18 total scores range from 0 to 65, with higher scores indicative of greater psychological distress.

Table 4 Intercorrelations among Study Variables

Variables	1.	2.	3.	4.	5.
1. Illness-related Parenting Stress	---	-.269*	-.456**	-.360**	.565**
2. Self-efficacy	---	---	.629**	.318**	-.343**
3. Mindfulness	---	---	---	.446**	-.543**
4. Perceived Social Support	---	---	---	---	-.461**
5. Psychological Distress	---	---	---	---	---

*Note.* \*Denotes correlation significant at  $p < .05$  (2-tailed). \*\*Denotes correlation significant at  $p < .001$  (2 tailed).

A series of preliminary analyses were conducted to determine associations between parent, child, and family demographic variables (parent age, parent gender, child age, child gender, race, parental education, approximate annual income, marital status, child to adult ratio in the home, caregiver and spouse physical and mental health status); child illness characteristics (illness severity as rated by the pediatric cardiologist, presence of an additional medical

condition); and the main variables of interest (parenting stress, mindfulness, self-efficacy, perceived social support, and psychological distress).

A series of independent samples *t*-tests were conducted to compare parenting stress frequency (PIP-F) and difficulty (PIP-D) ratings in our sample to samples of parents of children diagnosed with other chronic illnesses. There was a significant difference in parenting stress frequency ratings (PIP-F) in parents in our sample ( $M = 95.6$ ,  $SD = 28.2$ ) compared to ratings made by parents of children with inflammatory bowel disease ( $M = 84.4$ ,  $SD = 27.9$ ;  $t(129) = -2.2$ ;  $p < 0.05$ ; Guilfoyle et al., 2012) and parents of children with sickle cell disease ( $M = 105.4$ ,  $SD = 27.3$ ;  $t(137) = -2.1$ ;  $p < 0.05$ ; Logan et al., 2002). No significant differences in frequency ratings were found between our sample and samples of parents of children with cancer, obesity, or diabetes. There was a significant difference in parenting stress difficulty ratings (PIP-D) when comparing parents in our sample ( $M = 87.3$ ,  $SD = 31.8$ ) to parents of children with inflammatory bowel disease ( $M = 78.2$ ,  $SD = 25.2$ ;  $t(129) = -1.8$ ;  $p < 0.05$ ; Guilfoyle et al., 2012) diabetes ( $M = 78.11$ ,  $SD = 26.1$ ;  $t(201) = 2.1$ ;  $p < 0.05$ ; Streisand et al., 2005), and cancer ( $M = 112.4$ ,  $SD = 35.1$ ;  $t(193) = -5.1$ ;  $p < 0.05$ ; Streisand et al., 2005). No significant differences in difficulty ratings were found between our sample and samples of parents of children with cancer, obesity, or diabetes.

Pearson's correlations revealed a significant positive correlation between caregiver education and parenting stress ( $r = .27$ ,  $p = .03$ ). Independent samples *t* tests revealed no significant differences in parenting stress, social support, mindfulness, self-efficacy, or psychological functioning between males and females. However, when parenting stress was compared at the subscale level, female caregivers ( $M = 88.53$ ,  $SD = 32.81$ ) reported greater difficulty than male caregivers ( $M = 74.54$ ,  $SD = 12.66$ );  $t(13.01) = -2.11$ ,  $p = 0.02$ . Given that

significant differences were not found at the scale level, data from both female and male primary caregivers were included in subsequent analyses.

Analyses revealed a statistically significant difference with participants who endorsed that their child had an additional chronic medical condition reporting higher parenting stress ( $M = 207.8$ ,  $SD = 53.05$ ) than those who did not ( $M = 176.3$ ,  $SD = 54.69$ ),  $t(63) = -2.09$ ,  $p = 0.04$ . Analyses of Variance (ANOVAs) revealed a statistically significant difference in parenting stress among races,  $F(4,64) = 4.31$ ,  $p < .001$ . Follow up  $t$  tests indicated that the mean parenting stress score for “Other” ( $M = 246.4$ ,  $SD = 66.17$ ) was significantly higher from “Black or African American” ( $M = 162.6$ ,  $SD = 53.78$ ). No significant differences in parenting stress, self-efficacy, mindfulness, perceived social support, or psychological functioning existed between any other demographic groups.

Pearson product-moment correlations revealed significant negative correlations between illness-related parenting stress and mindfulness ( $r = -0.46$ ,  $p < .001$ ), self-efficacy ( $r = -0.30$ ,  $p = .02$ ), and perceived social support ( $r = -0.36$ ,  $p < .01$ ). Illness-related parenting stress positively correlated with psychological distress ( $r = 0.57$ ,  $p < .001$ ). Positive correlations were also found between mindfulness and social support ( $r = 0.45$ ,  $p < .01$ ). Mindfulness ( $r = -0.54$ ,  $p < .001$ ), self-efficacy ( $r = -0.34$ ,  $p < .01$ ), and social support ( $r = -0.46$ ,  $p < .001$ ) were negatively associated with psychological distress.

Regression assumptions (i.e., assumptions of normality, independence, linearity, homoscedasticity, and outliers) were checked for violations (Field, 2009). Primary predictor and outcome variables were tested for normality using Shapiro-Wilk and skewness coefficients. Violations in normality were revealed for the variable psychological functioning ( $W = .813$ ,  $p < .001$ ). Psychological functioning was highly positively skewed (skewness = 1.62). A natural log

data transformation was used to create a normally distributed variable for statistical analyses. The variable self-efficacy also violated assumptions of normality ( $W = .964, p = .04$ ), and was somewhat negatively skewed (skewness =  $-.594$ ). A reflect and square root data transformation was used to create a normally distributed variable for statistical analyses. Similarly, the variable perceived social support ( $W = .884, p < .001$ ) violated assumptions of normality. Social support was highly negatively skewed (skewness =  $-1.39$ ). A reflect and square root data transformation was used to create a normally distributed variable for statistical analyses. The Durbin-Watson statistic was within the acceptable range between 1.4 and 2.6 satisfying the assumption of independence of errors. Tolerance and VIF scores were used to assess for the presence of multicollinearity; scores were in the acceptable range for all variables. Assumptions of homoscedasticity and normality of the error distributions were satisfied as residuals were normally distributed across levels of the predictor.

### **3.2 Primary Analyses**

Given the restricted sample size, the following results should be interpreted with caution. A hierarchical regression analysis was conducted to test the unique predictive value of illness-related parenting stress, self-efficacy, perceived social support, and mindfulness on parents' psychological distress. Parenting stress, perceived social support, mindfulness, and self-efficacy were entered into the first step of the regression. The total variance in psychological functioning explained by the model as a whole was 49% [ $R^2 = 0.49, F(3,63) = 8.05, p < .001$ ]. Regression analyses revealed that illness-related parenting stress ( $\beta = 0.43, t(63) = 4.18, p < 0.001$ ) and mindfulness ( $\beta = -0.31, t(63) = -2.26, p = 0.03$ ) were statistically significant predictors of psychological functioning in the final model. Neither self-efficacy ( $\beta = -0.11, t(63) = -0.88, p =$



0.38) nor social support ( $\beta = 0.21$ ,  $t(63) = 1.97$ ,  $p = 0.05$ ) were statistically significant predictors of psychological functioning in the final model.

*Table 5 Regression Analysis for Variables Predicting Psychological Distress*

Variable	<i>t</i>	<i>df</i>	$\beta$	<i>p</i>
Illness-related parenting stress	4.18	63	0.43	< 0.001
Mindfulness	-2.26	63	-0.31	0.03
Perceived Social Support	1.97	63	0.21	0.05
Self-efficacy	-0.88	63	-0.11	0.38

## 4 DISCUSSION

The purpose of the current study was to describe family demographic and child disease-related characteristics and examine the extent to which illness-related parenting stress and coping resources (i.e., mindfulness, self-efficacy, and perceived social support) relate to psychological functioning in primary caregivers of young children diagnosed with congenital heart disease. Sixty-nine primary caregivers of children 15 days to 3 years old with congenital heart disease completed measures of demographics, illness-related parenting stress, mindfulness, self-efficacy, social support, and psychological adjustment.

### 4.1 Specific Aim 1

The current sample was racially diverse and included mostly married mothers in their early 30's. Although the mean parental education in this sample indicated some college completion ( $M = 14.94$  years), a large portion of participants reported either high school education or less ( $n = 19$ , 28%) or college or graduate degree ( $n = 34$ , 49%), suggesting somewhat of a dichotomy within the sample. Although mean annual income in this sample was approximately middle-class status, it should be noted that a majority of participants reported

annual income less than \$40,000 or more than \$90,000, indicating a larger percentage of participants were in lower and upper SES than middle SES. The variability in racial diversity, income, and parental education in our sample was not too surprising given that recruitment was conducted at a major urban medical center.

When comparing the current sample to previous samples of parents with young children diagnosed with CHD found in the literature, the current sample appeared to be similar in age and marital status (Doherty et al., 2008; Lawoko & Soares, 2002, 2006; Tak & McCubbin, 2002), but represented greater racial diversity (Landolt, Buechel, & Latal, 2011; Lawoko & Soares, 2006), and had a greater percentage of participants with education less than or equal to a high school education (Hearps, 2014; Lawoko & Soares, 2002, 2006). The current sample included a patient age range and time since diagnosis similar to few comparison samples (e.g., Utens et al., 2002). Most comparison samples focused on examining parental psychological outcomes immediately following cardiac repair (Bevilacqua et al., 2013; Doherty et al., 2008; Hearps, 2014; Landolt, Buechel, & Latal, 2011) or many years following diagnosis and initial cardiac repair (Lawoko & Soares, 2006). In contrast to comparison samples of parents with children with CHD (Doherty et al., 2008; Hearps, 2014), the current sample had a wider range of illness severity. For example, participants in the study conducted by Doherty et al. (2008) were all parents of infants whose illness severity was categorized as complex. Similarly, participants in the study conducted by Hearps et al. (2014) enrolled children whose congenital heart defect required surgical repair. It should be noted that many of these comparison samples came from studies conducted with European, Asian, or Australian populations. Thus, it is not surprising that there would be demographic differences.

All participants identified themselves as their child's primary caregiver and no

statistically significant differences existed between males and females in parenting stress, mindfulness, self-efficacy, social support, or psychological distress. Thus, data from both mothers and fathers were included in all analyses. Prior studies have identified differences in stress (Bevilacqua et al., 2013), coping (Utens et al., 2000) and psychological functioning (Bevilacqua et al., 2013; Lawoko & Soares, 2006) between mothers and fathers of children with CHD; however, these differences did not exist in our sample. However, fathers represented a small percentage of the participants in the current study. In the current study, all parents identified as “primary” caregivers. Previous studies were either unclear or did not specify the type of caregiving role (e.g., primary versus secondary) played by the enrolled parents. Thus, it could be that differences in psychological functioning between mothers and fathers in other studies are due to the unequal division of caregiving duties between primary and secondary caregivers. When parenting stress was considered at the subscale level, fathers reported significantly lower difficulty ratings than mothers. Given that a larger percentage of male primary caregivers had additional adults in the home than did female caregivers, one explanation for males appraising events as less difficult could be the presence of and support from other caregivers in the home.

Our data indicated that participants who self-described as “Other” had higher parenting stress than participants who identified as “Black or African American.” It should be noted that those who identified as “Other” provided additional information that indicated they may have emigrated from other countries or identified as multiracial. It could be that immigrants or multiracial parents experience greater stress; however, given that participants who indicated “Other” represented a small portion of the sample (i.e., 7.2%) and appear to be a diverse group of individuals, it remains speculative as to why they may be experiencing higher stress. However,

some evidence in the pediatric cardiac literature suggests foreign nationality may impact mothers' health-related quality of life, as it impacts language and communication in the context of their child's healthcare system (Landolt, Buechel, & Latal, 2010). Similarly, evidence suggests that immigrants may experience acculturative stress as they navigate new unfamiliar systems (Thomas, 1995), which could impact parenting stress within an unfamiliar healthcare system.

Pediatric literature suggests that a negative relation exists between maternal education, which is often a proxy for family socioeconomic status, and psychological outcomes (Canning, Harris, & Kelleher, 1996; Manuel, 2001). In contrast to the current literature, results from the current study indicated that parental education was positively associated with parenting stress in primary caregivers of children with CHD. Parent's health literacy and expectations of themselves and their child may impact how they experience their child's illness and treatment. Parents in this sample with higher education may possess differences in their understanding of their child's illness severity and necessary medical treatment, which could impact the way they perceive their child's condition. Although employment data was not directly collected in this sample, primary caregivers with higher education may be more likely to be employed. Managing employment and child medical care has been shown to cause significant strain for primary caregivers (Major, 2003).

Previous studies have found that child illness parameters are not associated with parenting stress and mental health outcomes in parents of children with CHD (Doherty et al., 2008; Lawoko & Soares, 2006). As expected, illness severity was not a significant predictor of coping resources, parenting stress, or psychological functioning. However, the presence of an additional medical condition in children, including both chronic medical conditions (e.g., asthma,

lung disease) and genetic syndromes (e.g., DiGeorge's Syndrome, Down's Syndrome), was significantly associated with higher parenting stress in this sample. Thus, the presence of additional medical diagnoses or genetic syndromes may add to the caregiving burden, necessity for specialized care, and management of medical appointments and therapies for the child.

## **4.2 Specific Aim 2**

Aim 2 focused on exploring illness-related parenting stress, mindfulness, self-efficacy, and perceived social support in primary caregivers of young children with CHD. In line with challenges faced by parents of children with other conditions (Cousino & Hazen, 2013), illness-related parenting stress is a significant concern for primary caregivers of young children with CHD. Parents in our sample reported a higher frequency of illness-related parenting stressors compared to parents of children diagnosed with inflammatory bowel disease but lower compared to parents of children with sickle cell disease. Parents reported a similar frequency of potential stressors to parents of children with cancer, obesity, or diabetes. When rating the difficulty of potential stressors, parents in our sample appraised stressors as more difficult than parents of children diagnosed with inflammatory bowel disease or diabetes and less difficult than parents of children diagnosed with cancer. Parents in our sample appraised the difficulty of potential stressors similarly to parents of children with cancer, obesity, or diabetes. These results highlight the shared and unique illness-related parenting stress between pediatric illnesses. Differences in the frequency of stressors endorsed and appraisal of the difficulty of these stressors may reflect variation in illness severity and need for medical management, time point in patient's course of treatment, time point of recruitment, or other illness-specific factors. Differences in frequency of stressors and appraisal of the difficulty of these stressors within a sample could allow for more tailored parent intervention. For example, parents could be offered

or encouraged to seek more practical support to lessen the frequency of stressors or offered specific emotional support regarding the difficulty of specific stressors.

Although mindfulness previously has not been examined in parents of children with CHD, the mean mindfulness total score as assessed by the Cognitive and Affective Mindfulness Scale-Revised (CAMS-R), was similar to adults prior to attending a mindfulness-based stress reduction program at a major medical center (Greeson et al., 2011). This suggests parents in our sample report similar levels of mindfulness to other adults without mindfulness training.

Prior evidence suggests parents of children diagnosed with chronic illnesses experience social isolation (Patterson & McCubbin, 1983). However, perceived social support scores in this sample were highly skewed, with a majority of participants endorsing high levels of perceived social support. Given the typical timeline for cardiac surgical repairs within the first years of an infant's life, exposure to significant stressors and illness-related parenting stress may initially be more acute (Backer & Mavroudis, 2007; Taks & McCubbin, 2002). Compared to other chronic illnesses populations that may have a longer course but do not require surgery, it may be easier for primary caregivers of children with CHD to ask for and receive support when they experience acute stressors, such as surgical repairs and hospitalizations.

The General Self-efficacy Scale was modified to target primary caregivers' self-efficacy for managing their child's medical condition, as self-efficacy is topic-specific. Prior literature indicates parents of children with CHD report considerably higher doubts related to their competency in caring for their infant with CHD when compared to parents of healthy children and children with cystic fibrosis (Goldberg et al., 1990) and Down Syndrome (Pelchat et al., 1999). In contrast to prior evidence, self-efficacy scores in this sample were skewed, indicating that many participants in the current sample reported high levels of self-efficacy to manage their

child's illness. Studies conducted by Goldberg et al. (1990) and Pelchat et al. (1999) focused specifically on parents' early beliefs in their competence to manage their infants' illness prior to six months of age. Thus, high self-efficacy reported by the current sample may reflect parents' increasing self-efficacy as they manage their child's CHD throughout the first few years.

Psychological functioning scores, assessed by the Brief Symptom Inventory-18 (BSI-18; Derogatis, 2003) were skewed toward healthy psychological functioning. This is important to note as it renders the mean global severity index less clinically relevant for interpretation than the percentage of participants who endorsed symptoms within a clinical range. The BSI-18 standard case-rule classifies global severity index *t*-scores greater than or equal to 63 as clinical cases (Derogatis, 2001). Alternative case-rules have been generated to maximize sensitivity and specificity and avoid missing respondents who may not meet criteria for the standard case-rule but would likely benefit from further assessment or psychological support (Recklitis & Rodriguez, 2007; Zabora et al., 2001). The Zabora case-rule considers GSI *t*-scores of 57 or greater clinical cases; the Recklitis case-rule is the most inclusive and identifies a *t*-score of 50 as the clinical cutoff for positive case identification. Based on the standard case-rule, seven participants in this study met criteria for psychological distress. However, when the most inclusive case-rule was used to determine the clinical cut-off, 24 participants (35%) met criteria for psychological distress. Three males (50% of males) and 21 females (33% of females) endorsed symptoms of psychological distress in the clinical range.

Despite the inconsistencies in measurement (e.g., various inventories administered) and potential sociopolitical differences between study locations within the CHD literature, psychological distress reported in this sample was similar to psychological distress found in other samples of parents with children of CHD (Doherty et al, 2009; Hearps et al., 2014; Lawoko

& Soares, 2006). Specifically, Hearps et al. (2014) found 38.5% of parents of infants within four weeks of cardiac surgical repair fell in the clinical range for psychological distress. Similarly, evidence from Doherty et al. (2009) suggested 33% of female and 18% of male caregivers in their sample of parents of infants with recent cardiac surgical repairs reported psychological distress in the clinical range (Doherty et al., 2009). Furthermore, evidence from a longitudinal study of parents of youth (age 0 to 20) with CHD conducted by Lawoko and Soares (2006) suggested that clinical levels of psychological distress persist for parents beyond the immediate distress surrounding surgical repair. Parents reported depression, anxiety, and somatization scores (16-38%) at time point 1; seven to 22% reported persisting psychological distress one year later (Lawoko & Soares, 2006). Given the variation in sociopolitical contexts between countries in which studies have been conducted (e.g., access to national healthcare and educational resources), it would not be surprising if parents' experience of their child's illness also varied. However, evidence from the current study supports that psychological functioning appears to be similar in parents of young children diagnosed with CHD, regardless of the country in which they reside. This highlights the importance of identifying correlates of psychological distress beyond demographic factors.

### **4.3 Specific Aim 3**

The third aim was to examine the extent to which parenting stress and coping resources predicted psychological functioning in primary caregivers of young children with CHD. Specifically, it was hypothesized that higher parenting stress, lower mindfulness, lower perceived social support, and lower self-efficacy would each significantly predict higher parent psychological distress.

Substantial evidence from general and illness-specific parenting literature (Cousino &



Hazen, 2012; Gelfand, Teti, & Radin, 1992; Miller, Gordon, Daniele, & Diller, 1992) and CHD literature (Doherty et al., 2008; Lawoko & Soares, 2006) indicates that parenting stress and caregiving burden are associated with parental psychological functioning. It was hypothesized that illness-related parenting stress would predict psychological distress in this sample. As predicted, zero-order correlations revealed a strong correlation between illness-related parenting stress and psychological functioning in this sample. Consistent with hypotheses and previous research, illness-related parenting stress explained a significant portion of the variance in psychological functioning in the regression model. Due to the cross-sectional study design, the directionality of the relation between stress and psychological distress cannot be determined. However, evidence suggests that heightened stress reactivity is a significant predictor of depressive symptoms (Felsten, 2004). Furthermore, longitudinal studies have demonstrated that heightened stress reactivity precedes depressive symptoms (Bouteyre, Maurel, & Bernaud, 2007), suggesting that the way an individual assesses and reacts to stressors has a considerable impact on their psychological adjustment. Findings from the current study support that both the number of illness-related stressors and the primary caregivers' appraisals of these stressors may contribute to their psychological functioning. Parents of young children with CHD are exposed to multiple, inevitable illness-related stressors. Appraising stressors as more demanding or threatening is associated with psychological distress. In a review of daily stress and depression, Sher (2004) emphasized the importance of preventing depression by targeting emotional and behavioral stress reactions. Alternately, poor psychological functioning could impact caregivers' cognitive appraisals of stressors. If psychological functioning is indeed impacting the way stressors are appraised, cognitive appraisals of stress serve as a modifiable target for intervention. Evidence supports that mindfulness protects against negative psychological

outcomes in parents of children with chronic illnesses (Minor, Carlson, MacKenzie, Zernicke, & Jones, 2006); however, this is the first study to examine mindfulness in parents of young children with CHD. Given the positive impact of mindfulness on caregivers' psychological outcomes in caregivers (Birnie, Garland, & Carlson, 2010; Haines, 2014; Minor, Carlson, MacKenzie, Zernicke, & Jones, 2006), it was hypothesized that mindfulness would predict psychological functioning in parents of children with CHD. As expected, a strong negative correlation between mindfulness and illness-related parenting stress was found. Mindfulness also explained a unique portion of the variance in psychological functioning in the regression analyses. This suggests mindfulness could be protective against psychological distress even in the presence of multiple stressors. Primary caregivers who have more cognitive awareness and non-judgmental acceptance of the present moment are more equipped to experience illness-related stressors and are at lower risk for psychological distress. These components of mindfulness are alternatives to worry, rumination, and experiential avoidance (Crane, 2009), which contribute to psychological distress. For example, while managing their child's daily medical care, a primary caregiver demonstrating awareness and non-judgmental acceptance of their present experience would be better able to acknowledge and let go of distressing thoughts and emotions that may arise). Consistent with literature that suggests mindfulness influences an individual's reaction to stressors (Britton, Shahrar, Szepsenwol, & Jacobs, 2012; Keng et al., 2011), the relation between mindfulness and illness-related parenting stress in the current study supports the use of mindfulness in combatting psychological distress by targeting the way caregivers appraise illness-related stressors. Again, given the lack of longitudinal or experimental data in this study, causality cannot be determined between illness-related parenting stress, mindfulness, and psychological distress. It is also possible other unknown variables could be driving the

associations between variables.

Previous evidence suggests there is a negative association between perceived social support and psychological distress in parents of children diagnosed with CHD (Lawoko & Soares, 2006). It was hypothesized that perceived social support would predict a unique portion of the variance in psychological functioning in this sample. Consistent with prior literature, zero-order correlations revealed a strong negative correlation between perceived social support and psychological functioning in this sample. However, after accounting for the variance in psychological functioning explained by other predictor variables in the model, perceived social support only approached significance as a predictor of psychological functioning in the regression analyses. Pearson's product moment correlations revealed strong intercorrelation between the variables perceived social support and illness-related parenting stress, which both partially reflected parents' appraisals of the level of demand associated with their child's illness. Thus, the shared variance between these two constructs may have impacted the results of the regression.

The measure of social support used provides a basic assessment of participants' perception of the existence and quality of emotional support from friends, family, a special person, and healthcare providers but does not assess the amount of actual or perceived tangible assistance (e.g., financial assistance, assistance with child medical care) they receive from others. Although primary caregivers reported high levels of perceived social support, this emotional support may not translate into the tangible assistance required for managing illness-specific demands in daily life. The function of the social support may be valuable information in development of effective interventions.

Given relations between parents' belief in their competence to manage their child's

illness and elevated parenting stress (Goldberg et al., 1990; Pelchat et al., 1999), it was hypothesized that self-efficacy would predict psychological functioning. Zero-order correlations revealed a strong negative correlation between self-efficacy and psychological functioning in this sample. However, after accounting for the variance in psychological functioning explained by illness-related parenting stress, self-efficacy did not explain a unique portion of the variance in psychological functioning in the regression analyses. Pearson's product moment correlations revealed strong intercorrelation between the variables self-efficacy and illness-related parenting stress. A primary caregiver's belief in their competence and ability to manage illness-related demands relates to the caregiver's appraisal of the difficulty of a potentially stressful event related to their child's CHD, especially given the illness-specific content added to the general self-efficacy measure. Thus, the shared variance between these two constructs may have impacted the regression results.

Considering the significant portion of parents in this sample reporting psychological distress, these results highlight the importance of illness-related parenting stress and mindfulness for screening and intervention purposes. However, the current model accounts for only 49% of variance. Thus, parents' level of understanding of medical condition, genetic predisposition, personality traits, and other risk factors and coping resources may account for other variance in psychological functioning in parents of young children with CHD.

#### **4.4 Limitations and Future Directions**

Cautious interpretation of the results is needed given limitations in the current study. While the sample size is comparable to other pediatric psychology research studies, the current study is underpowered. A larger sample size would be needed to sufficiently power multiple regression analyses with four predictor variables with the given effect sizes. A larger sample size

would also allow for more advanced and robust statistical analyses, including moderation and mediation analyses necessary to test Lazarus and Folkman's transactional model of stress and coping (Lazarus & Folkman, 1984). Better understanding the interactions and mechanisms between demographics, illness-related parenting stress, mindfulness, and psychological distress would further enhance screening for parents with the greatest need for psychological support. The cross-sectional study design in the current study does not allow for determining causal relations between variables. Future research could utilize longitudinal designs to determine the causal relations between illness-related parenting stress, mindfulness, and psychological functioning. This type of research could be valuable in determining if illness-related parenting stress and mindfulness are predictive of psychological distress, which would allow for more effective identification of parents at the highest risk of psychological distress even before symptoms of psychological distress present.

Given that recruitment took place in an outpatient medical setting, primary caregivers who attended scheduled appointments were recruited. Caregivers who were running excessively late, did not show up to appointments, or required multiple appointments to be rescheduled were less likely to be approached for recruitment. Caregivers with the most medically unstable children were also less likely to be approached for recruitment, as they were more likely to require inpatient rather than outpatient care. These caregivers, along with caregivers who may have declined participation in the study due to high levels of stress, represent a sample of the population that may be at the highest risk for psychological distress.

This study also relied solely on participant self-report measures of stress, coping, and psychological functioning. Participants experiencing high levels of parenting stress and low levels of coping may have completed surveys less thoroughly or honestly. Presence of higher

stress or psychological functioning or fewer available coping resources also may have impacted survey completion during the clinic appointment. Evidence suggests that a strong bias exists for underreporting depressive symptoms (Eaton, Neufeld, Chen, & Cai, 2000). Participants endorsing more sensitive items or experiencing more emotional arousal while completing questionnaires may have been less likely to complete and return packets. Response bias may have occurred on coping measures as participants may have responded in a more favorable to items pertaining to their self-efficacy for managing their child's illness or perceived social support from healthcare providers. Future studies could incorporate healthcare professionals' perceptions, observational assessments of participants' coping and stress from their partners or family members, or objective records (e.g., healthcare utilization data) of caregivers' functioning to corroborate participant self-report. Inclusion of healthcare providers and family members may provide unique, less biased insight regarding caregivers' understanding and management of their child's illness and daily functioning.

Given the exclusion criteria of the study, many primary caregivers were not recruited due to a language barrier. Evidence supports that language and level of acculturation may significantly impact immigrants' healthcare utilization and ability to navigate the healthcare system (Bermúdez-Parsai et al., 2012) which could impact the burden of illness management and illness-related parenting stress. As a result, the results of the current study may be less generalizable to the entire population of primary caregivers of young children with CHD, which in a diverse major medical center, includes many languages other than English.

CHD illness severity was categorized as simple, moderate, or complex by one pediatric cardiologist. Although published guidelines for determining CHD illness severity were provided, the pediatric cardiologist also used professional expertise and judgment to categorize each

patient's illness severity. Although the method of one pediatric cardiologist rating illness severity simplified categorization and reduced potential differences between raters, it did not allow for interrater reliability. To increase the replicability of the study, future research should include multiple raters and more detailed analysis of any judgments made by the cardiologist that contradicted the guidelines.

The current study included genetic syndromes as well as medical diagnoses in the additional medical conditions variable. Thus, future research is needed to differentiate the impact of genetic syndromes and additional medical diagnoses on parental psychological outcomes. Variation in number and severity of other medical diagnoses may also have a significant impact on how parents' experience their child's CHD diagnosis.

#### **4.5 Clinical Implications**

Despite these limitations, the current study provides valuable information regarding primary caregivers' exposure to and appraisal of stressors and demands related to their child's CHD and the potentially protective nature of the coping resource mindfulness. This study emphasizes that for a portion of primary caregivers of young children with CHD, psychological functioning appears to persist beyond patients' initial surgical repairs and not be associated with child illness severity. The persistent nature of psychological functioning highlights the need for psychological screening to identify primary caregivers at the highest risk for psychological distress. Early detection of psychological functioning is needed to best support caregivers. Evidence from the current study supports that illness-related parenting stress and mindfulness may be important factors to consider in screening for psychological distress. Caregivers who experience greater illness-related parenting stress and endorse lower mindfulness may be higher risk for psychological functioning and could be targeted for intervention. Extensive evidence

supports the positive impact of mindfulness and brief Mindfulness-Based Stress Reduction programs on stress and psychological distress. These interventions have demonstrated utility for caregivers of patients with chronic conditions (Birnie, Garland, & Carlson, 2010; Haines et al., 2014). Parents experiencing elevated stress related to raising a child with a chronic condition reported substantial reductions in stress symptoms after participation in an 8-week Mindfulness-Based Stress Reduction intervention program (Minor et al., 2006). The strong associations between mindfulness, illness-related parenting stress, and psychological functioning in this sample suggest that Mindfulness-Based Stress Reduction or Mindfulness-Based Cognitive Therapy (Morgan, 2003) interventions might be well-suited to support parents and improve psychological functioning.

#### **4.6 Conclusions**

Overall, primary caregivers of young children with CHD reported illness-related parenting stress similar to parents of other pediatric illness populations. Mindfulness in this sample was comparable to other populations of caregivers for patients with chronic conditions. This sample reported high perceived social support and self-efficacy. Although many primary caregivers adjusted to their child's CHD, a percentage of primary caregivers reported clinical levels of psychological distress, suggesting that risk for psychological distress persists beyond initial diagnosis and surgical repairs for some primary caregivers. Illness-related parenting stress and coping resources (i.e., mindfulness, self-efficacy, and social support) all correlated to psychological functioning in the expected directions, but only illness-related parenting stress and mindfulness explained a unique amount of the variance in psychological functioning in the regression analyses. In conclusion, these data provide some initial evidence to support that interventions incorporating stress appraisals and mindfulness may be well-suited to prevent and



treat psychological distress in parents of young children with CHD.

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## APPENDICES

### Appendix A Background Information Form

1. Your relation to child: \_\_\_\_ Mother \_\_\_\_ Father \_\_\_\_ Grandparent

If other, please describe: \_\_\_\_\_

2. Are you the primary caregiver for the child?      **YES**    **NO**

3. Your gender (circle response): Male    Female

4. Your age: \_\_\_\_\_

5. Your Race:

\_\_\_\_ American Indian or Alaska Native

\_\_\_\_ Asian

\_\_\_\_ Black or African American

\_\_\_\_ Native Hawaiian

\_\_\_\_ Other Pacific Islander

\_\_\_\_ White

If other,

describe: \_\_\_\_\_

6. Your Marital Status (circle): Single    Married    Separated    Divorced    Widowed

7. Highest education you have completed: \_\_\_\_\_

8. Please circle your approximate total family income per year:

a. Up to \$10,000

b. \$10,001 – 20,000

c. \$20,001 – 30,000

f. \$50,001 – 60,000

g. \$60,001 – 70,000

h. \$70,001 – 80,000

d. \$30,001 – 40,000

i. \$80,001 – 90,000

e. \$40,001 – 50,000

j. \$90,000 and above

9. Do you have a chronic medical condition (e.g., asthma, chronic pain, diabetes, etc.)?

YES NO

If so, what kind(s)

---

10. Does your spouse/partner have a chronic medical condition? **YES NO**

If so, what kind(s) \_\_\_\_\_

11. Have you been diagnosed with a psychological disorder (i.e., anxiety, depression, etc.)?

**YES NO**

If so, what \_\_\_\_\_

12. Has your spouse/partner been diagnosed with a psychological disorder? **YES NO**

If so, what \_\_\_\_\_

**Questions about your child**

13. Child's gender: \_\_\_Male \_\_\_Female

14. Child's age: \_\_\_ yrs. \_\_\_ mos.

15. Child's race:

\_\_\_American Indian or Alaska Native

\_\_\_Asian

\_\_\_Black or African American

\_\_\_Native Hawaiian

\_\_\_ Other Pacific Islander

\_\_\_ White

16. How many other children live in the home? \_\_\_ What are their ages? \_\_\_\_\_

17. How many other adults live in the home? \_\_\_\_\_ What are their ages? \_\_\_\_\_

18. What type of chronic congenital heart defect does your child have? \_\_\_\_\_

19. Was your child's heart defect diagnosed during pregnancy or after birth?

a. If during pregnancy, during what month of pregnancy was the diagnosis made?

\_\_\_\_\_

b. If after birth, how old was your child when they were diagnosed?

\_\_\_\_\_ years \_\_\_\_\_ months \_\_\_\_\_ days

20. How many cardiac surgeries has your child had? \_\_\_\_\_

21. When was your child's first surgery? \_\_\_\_\_

22. When was your child's most recent surgery? \_\_\_\_\_

23. Has your child received a heart transplant? \_\_\_\_\_

24. Does your child have a chronic illness or medical condition besides congenital heart disease?

**YES NO**

If so, what? \_\_\_\_\_

25. What medication(s) is your child prescribed? \_\_\_\_\_

\_\_\_\_\_

26. What major complications has your child experienced related to their congenital heart disease?

\_\_\_\_\_

27. How many days of work have you missed due to your child's illness in the past year?

\_\_\_\_\_

28. Would you be willing to allow us to keep you and your child's contact information for follow-up or future research projects?

**YES NO**

If YES, please provide your contact information below:

Your Name: \_\_\_\_\_

Phone #: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

## Appendix B Pediatric Inventory for Parents

Below is a list of difficult events which parents of children who have (or have had) a serious illness sometimes face. Please read each event carefully, and circle **HOW OFTEN** the event has occurred for you in the past 7 days, using the 5 point scale below. Afterwards, please rate how **DIFFICULT** it was/or generally is for you, also using the 5 point scale. **Please complete both columns for each item.**

EVENT	HOW OFTEN? (Past 7 days)					HOW DIFFICULT?				
	Never	Rarely	Sometimes	Often	Very Often	Not at all	A little	Somewhat	Very Much	Extremely
1. Difficulty sleeping	Never	Rarely	Sometimes	Often	Very Often	Not at all	A little	Somewhat	Very Much	Extremely
2. Arguing with family member(s)	Never	Rarely	Sometimes	Often	Very Often	Not at all	A little	Somewhat	Very Much	Extremely
3. Bringing my child to the clinic or hospital	Never	Rarely	Sometimes	Often	Very Often	Not at all	A little	Somewhat	Very Much	Extremely
4. Learning upsetting news	Never	Rarely	Sometimes	Often	Very Often	Not at all	A little	Somewhat	Very Much	Extremely
5. Being unable to go	Never	Rarely	Sometimes	Often	Very	Not at	A little	Somewhat	Very	Extremely



to work/job					Often		all			Much	
6. Seeing my child's mood change quickly	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely
7. Speaking with doctor	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely
8. Watching my child have trouble eating	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely
9. Waiting for my child's test results	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely
10. Having money/financial troubles	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely
11. Trying not to think about my family's difficulties	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely
12. Feeling confused about medical information	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely
13. Being with my child during medical procedures	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely

14. Knowing my child is hurt or in pain	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely
15. Trying to attend to the needs of other family members	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely
16. Seeing my child sad or scared	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely
17. Talking with the nurse	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely
18. Making decisions about medical care or medicines	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely
19. Thinking about my child being isolated from others	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely
20. Being far away from family and/or friends	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely
21. Feeling numb inside	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely

22. Disagreeing with a member of the healthcare team	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely
23. Helping my child with his/her hygiene needs	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely
24. Worrying about the long term impact of the illness	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely
25. Having little time to take care of my own needs	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely
26. Feeling helpless over my child's condition	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely
27. Feeling misunderstood by family/friends as to the severity of my child's illness	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely
28. Handling changes in my child's daily medical routines	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely

29. Feeling uncertain about the future	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely
30. Being in the hospital over the weekends/holidays	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely
31. Thinking about other children who have been seriously ill	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely
32. Speaking with my child about his/her illness	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely
33. Helping my child with medical procedures (e.g.- giving shots, swallowing medicine, changing dressing)	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely
34. Having my heart beat fast, sweating, or feeling tingly	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely
35. Feeling uncertain about disciplining my	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely

child											
36. Feeling scared that my child could get very sick or die	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely
37. Speaking with family members about my child's illness	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely
38. Watching my child during medical procedures/visits	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely
39. Missing important events in the lives of other family members	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely
40. Worrying about how friends and relatives interact with my child	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely
41. Noticing a change in my relationship with my partner	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely

42. Spending a great deal of time in unfamiliar settings	Never	Rarely	Sometimes	Often	Very Often		Not at all	A little	Somewhat	Very Much	Extremely
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### Appendix C General Self-efficacy Scale Revised

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Using the following 1-4 scale, please indicate how you feel about each statement.

1 = Not at all true    2 = Hardly true    3 = Moderately true    4 = Exactly true

	<b>Not at all true</b>	<b>Hardly true</b>	<b>Moderately true</b>	<b>Exactly true</b>
1. I can always manage to solve difficult problems related to my child's health if I try hard enough.	<b>Not at all true</b>	<b>Hardly true</b>	<b>Moderately true</b>	<b>Exactly true</b>
2. If someone opposes me regarding my child's health, I can find the means and ways to get what I want.	<b>Not at all true</b>	<b>Hardly true</b>	<b>Moderately true</b>	<b>Exactly true</b>
3. It is easy for me to stick to my aims and accomplish my goals related to my child's health.	<b>Not at all true</b>	<b>Hardly true</b>	<b>Moderately true</b>	<b>Exactly true</b>
4. I am confident that I could deal efficiently with unexpected events related to my child's health.	<b>Not at all true</b>	<b>Hardly true</b>	<b>Moderately true</b>	<b>Exactly true</b>
5. Thanks to my resourcefulness, I know how to handle unforeseen situations regarding my child's health.	<b>Not at all true</b>	<b>Hardly true</b>	<b>Moderately true</b>	<b>Exactly true</b>

6. I can solve most problems related to my child's health if I invest the necessary effort.	<b>Not at all true</b>	<b>Hardly true</b>	<b>Moderately true</b>	<b>Exactly true</b>
7. I can remain calm when facing difficulties regarding my child's health because I can rely on my coping abilities.	<b>Not at all true</b>	<b>Hardly true</b>	<b>Moderately true</b>	<b>Exactly true</b>
8. When I am confronted with a problem related to my child's health, I can usually find several solutions.	<b>Not at all true</b>	<b>Hardly true</b>	<b>Moderately true</b>	<b>Exactly true</b>
9. If I am in trouble that is related to my child's health, I can usually think of a solution.	<b>Not at all true</b>	<b>Hardly true</b>	<b>Moderately true</b>	<b>Exactly true</b>
10. I can usually handle whatever comes my way regarding my child's health.	<b>Not at all true</b>	<b>Hardly true</b>	<b>Moderately true</b>	<b>Exactly true</b>



### Appendix D Cognitive and Affective Mindfulness Scale- Revised

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Please indicate how often each statement is true for you.

Using the following 1-4 scale, please indicate how you feel about each statement.

1 = Rarely/ Not at All    2 = Sometimes    3 = Often    4 = Almost Always

	<b>Rarely/ Not at All</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost Always</b>
1. It is easy for me to concentrate on what I am doing.	<b>Rarely/ Not at All</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost Always</b>
2. I can tolerate emotional pain	<b>Rarely/ Not at All</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost Always</b>
3. I can accept things I cannot change.	<b>Rarely/ Not at All</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost Always</b>
4. I can usually describe how I feel in the moment in considerable detail.	<b>Rarely/ Not at All</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost Always</b>
5. I am easily distracted.	<b>Rarely/ Not at All</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost Always</b>

6. It's easy for me to keep track of my thoughts and feelings.	<b>Rarely/ Not at All</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost Always</b>
7. I try to notice my thoughts without judging them.	<b>Rarely/ Not at All</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost Always</b>
8. I am able to accept the thoughts and feelings I have.	<b>Rarely/ Not at All</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost Always</b>
9. I am able to focus on the present moment.	<b>Rarely/ Not at All</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost Always</b>
10. I am able to pay close attention to one thing for a long period of time.	<b>Rarely/ Not at All</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost Always</b>

### Appendix E Multidimensional Scale of Perceived Social Support

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Using the following 1-7 scale, please indicate how you feel about each statement.

1	2	3	4	5	6	7
Very Strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildly Agree	Strongly Agree	Very Strongly Agree

	1	2	3	4	5	6	7
1. There is a special person who is around when I am in need.	1	2	3	4	5	6	7
2. There is a special person with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
3. My family really tries to help me.	1	2	3	4	5	6	7
4. I can talk about my problems with one of my child's healthcare providers.	1	2	3	4	5	6	7
5. I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7
6. My friends really try to help me.	1	2	3	4	5	6	7

7. I can count on my friends when things go wrong.	1	2	3	4	5	6	7
8. My child's healthcare providers really try to help.	1	2	3	4	5	6	7
9. I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
10. When I am in need, I can go to one of my child's healthcare providers.	1	2	3	4	5	6	7
11. My family is willing to help me make decisions.	1	2	3	4	5	6	7
12. I can talk about my problems with my friends.	1	2	3	4	5	6	7
13. There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7
14. I can talk about my problems with my family.	1	2	3	4	5	6	7
15. I get the emotional help and support I need from one of my child's healthcare providers.	1	2	3	4	5	6	7
16. I get the emotional help and support I need from my family.	1	2	3	4	5	6	7

## **Appendix F Guidelines for Categorizing CHD Severity**

### **Simple Congenital Heart Disease**

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An unrepaired small atrial septal defect (ASD) or patent foramen ovale (PFO)

Secundum or sinus venosus atrial septal defect (ASD) that was closed with sutures or a patch

Ventricular septal defect (VSD) that was closed with sutures or a patch

Patent ductus arteriosus (PDA) that was closed in early childhood

Pulmonary valve stenosis (mild)

### **Moderate Congenital Heart Disease**

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Presence of one or more defects that need complex repairs as an infant or young child or have a partly repaired defect; require ongoing treatment or more surgery as an adult

Aortic stenosis

Anomalous pulmonary venous drainage, total (TAPVR) or partial (PAPVR)

Secundum or sinus venosus atrial septal defect

Atrioventricular canal, complete (AVC) or partial (A-V Canal)

Coarctation of the Aorta

Ebstein anomaly

Infundibular right ventricular outflow obstruction (RVOTO)

Ostium primum atrial septal defect

Patent ductus arteriosus that was not closed (PDA)

Pulmonary valve regurgitation or insufficiency (moderate to severe)

Pulmonic valve stenosis (PS) – moderate to severe

Sinus of Valsalva fistula/aneurysm

Tetralogy of Fallot (TOF)

Ventricular septal defect (VSD) when there is any other congenital heart defect

Ventricular septal defect (VSD) which has not been closed

## **Complex Congenital Heart Disease**

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One or more defects that have not been repaired, have been only partly repaired, or require more than one surgery to repair

Conduits, valved or non-valved (homograft or Rastelli-type repair

Congenitally corrected transposition of the great arteries (1-TGA)

Cyanotic congenital hearts (all types)

Double outlet right ventricle (DORV)

Eisenmenger syndrome

Fontan procedure

Mitral atresia

Single ventricle- double inlet or outlet, common or primitive (SV or DILV)

Pulmonary atresia (PA) – all forms

Transposition of the great arteries (TGA)- repaired with Mustard/Senning procedure

Transposition of the great arteries (TGA)-repaired with atrial switch

Tricuspid atresia

Truncus arteriosus or hemi-truncus

Other complex defects (crisscross heart, isomerism, and heterotaxy syndromes)